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Follow-up to the World Summit for Social Development and the twenty-fourth special session of the General Assembly: review of relevant United Nations plans and programmes of action pertaining to the situation of social groups: equalization of opportunities for persons with disabilities

Views of Governments on the proposals contained in the report of the Special Rapporteur on Disability (E/CN.5/2002/4), especially on the suggested supplement to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

Report of the Secretary-General

Summary

In its resolution 2002/26 of 24 July 2002 entitled "Further promotion of equalization of opportunities by, for and with persons with disabilities and protection of their human rights", the Economic and Social Council requested the Secretary-General to seek the views of Member States on the proposals contained in the report of the Special Rapporteur on Disability (E/CN.5/2002/4), especially on the suggested supplement to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities, and to submit a substantive report to the Commission for Social Development at its forty-second session. The Secretary-General solicited the views of the Governments on the report and the proposed supplement to the Standard Rules in a note verbale dated 6 June 2003. The views contained in the replies from Governments to the note verbale are summarized in the present report.

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I. Introduction

1. At its fortieth session, from 12 to 22 February 2002, the Commission for Social Development examined the note by the Secretary-General transmitting the report of the Special Rapporteur on Disability of the Commission for Social Development on monitoring the implementation of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities on his third mandate, 2000-2002 (E/CN.5/2002/4). The report included, inter alia, the proposal of complementing the Standard Rules with a supplement, which aims at introducing new areas and complementing those areas that are not considered to be sufficiently developed in the Rules, on the basis of the experience gained during the mandates of the first Special Rapporteur.

2. In its resolution 2002/26 of 24 July 2002 entitled "Further promotion of equalization of opportunities by, for and with persons with disabilities and protection of their human rights", the Economic and Social Council requested the Secretary-General to seek the views of Member States on the proposals contained in the report of the Special Rapporteur, especially on the suggested supplement to the Standard Rules, and to submit a substantive report to the Commission for Social Development at its forty-second session.

3. The Secretary-General solicited the views of Governments on the report and the proposed supplement to the Standard Rules in a note verbale dated 6 June 2003. The views contained in the replies from Governments to the note verbale are summarized in section III below.

II. Summary of issues included in the proposed supplement

4. Since their adoption by the General Assembly in its resolution 48/96 of 20 December 1993, the Standard Rules on the Equalization of Opportunities for Persons with Disabilities have played a significant role in informing the elaboration of national policies and practices on disability in the entire world. It is widely agreed that over the last decade the application of the principles expressed in the Rules has greatly contributed to the diffusion of best practices on equalization of opportunities for persons with disabilities. However, the widespread application of the Rules has also led to identifying gaps and limitations in the scope of their action.

5. The proposed supplement to the Standard Rules originates from the analysis of the shortcomings and areas in need of improvement within them. The process was initiated by the first Special Rapporteur on Disability in his report to the Commission on Social Development at its thirty-sixth session (E/CN.5/2000/3). In that report the following were pointed out as issues to be further investigated: gender concerns; housing and communication issues; the needs of children and older persons; the needs of persons with developmental and psychiatric disabilities; and the needs of persons with disabilities in poverty situations.

6. The process of analysis that led to the elaboration of the proposed supplement to the Standard Rules is the product of the joint effort of many international organizations and individual experts, including organizations of persons with disabilities and the panel of experts attached to the Rules monitoring mechanism.

7. The proposed supplement brings into focus the specific needs of the most vulnerable among persons with disabilities. It specifically focuses on the following areas: (a) fundamental concepts; (b) adequate standard of living and poverty alleviation; (c) housing, including the issue of residential institutions; (d) health and medical care; (e) emergency situations; (f) access to the social environment; (g) communication issues; (h) personnel training; (i) gender; (j) children with disabilities and the family; (k) violence and abuse; (l) older persons; (m) developmental and psychiatric disabilities; (n) invisible disabilities; (o) suggested further initiatives in national policy and legislation.[1]

III. Views of Member States

8. As of 1 November 2003, 16 replies representing the views of 40 Governments were received in response to the note verbale sent by the Secretary-General. The response to the note verbale was very limited, representing approximately one fifth of the total number of Member States. Replies were received from Argentina, Burkina Faso, Cameroon, China, Cyprus, the Czech Republic, Honduras, Luxembourg, Madagascar, Malta, Oman, the Philippines, the Russian Federation, Serbia and Montenegro, Trinidad and Tobago as well as from the European Union on behalf of its 15 members and 10 accessing countries.[2]

9. As it appears clearly from the list of responding Member States, the geographical coverage of the contributions received was also quite limited. The largest number of contributions originated from Europe; replies from other regional groups included three Member States from Latin American and the Caribbean region, two from Africa and two from Asia. Most replies came from developed countries, while only one contribution was received from a least developed country (Burkina Faso).

10. The relatively low degree of interest expressed by Member States in articulating their views on the proposed supplement to the Standard Rules is open to interpretation. It may reflect a lack of specific interest for the inclusion of the proposed supplement in the Rules. It may also reflect the fact that many Governments tend to consider that the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities has become a more appropriate forum to discuss disability issues and instruments.

11. Argentina highlights the fact that disability is increasingly recognized at the international level as a human rights issue. It agrees that the Standard Rules have provided a fundamental contribution to the formulation of policies aiming at improving the enjoyment of rights by persons with disabilities. However, taking into consideration the process of elaboration of a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities and particularly the progress made during the second session of the Ad Hoc Committee on the Convention, Argentina suggests that no supplement to the Standard Rules should be adopted so as to avoid the overlapping of the two processes. Argentina also suggests that it would be preferable for the observations of the first Special Rapporteur to be taken into consideration during the process of elaboration of the Convention.

12. Burkina Faso suggests a list of actions and initiatives that should be taken in order to further the implementation and scope of the Standard Rules: multiply the seminars on the Standard Rules to the benefit of association leaders, public and private mass media, local communities, parliamentarians and members of Governments; strengthen the capacity of associations through functional literacy programmes and training in advocacy and social mobilization; improve the participation of persons with disabilities in civil society organizations; stimulate intersectoral coordination of rehabilitation and equalization of opportunities for persons with disabilities; strengthen the provision of technical aids and equipment; promote inclusive formal education for all children with disabilities; review and improve social protection provisions for persons with disabilities; further extend accessibility to buildings through ramps, to schooling and to appropriate health care, to vocational training and farming, to sport and leisure; and develop community-based rehabilitation programmes that involve families, disability organizations and institutions. Burkina Faso stresses the need for the United Nations, particularly the United Nations Voluntary Funds, to support the implementation of national programmes in favour of persons with disabilities.

13. Cameroon, while noting the operational relevance of the proposed supplement, expresses concern that the emphasis on special needs indirectly portrayed persons with disability as being permanently dependent. On the contrary, the supplement should convey a strong sense of how social integration could lead persons with disability to autonomy and sustainable livelihood. Cameroon also stresses that the implementation of the proposed supplement requires the mobilization of considerable financial, human and material resources far beyond those available in developing countries, particularly those faced with serious economic difficulties. Cameroon observes with appreciation that the term "persons with disabilities" is now used to qualify persons of all ages with disabilities and it systematically refers to men and women with disabilities.

14. With regard to section B of the proposed supplement, on adequate standard of living and poverty alleviation, Cameroon emphasizes that poverty critically aggravates the often precarious situation of many persons with disabilities. Regarding section I, on gender, it highlights the fact that women with disabilities are often exposed to multiple discriminations: as women, as persons with disabilities and as economically weak subjects. As a consequence, women with disabilities face enormous difficulties in their social integration. As to section J, on children with disabilities and the family, Cameroon reaffirms that the place of children is within their families and in society and that this principle must be recognized and protected. It also highlights the importance of disability prevention and early rehabilitation. With regard to the proposition contained in paragraph 70 that "States should support women and men with disabilities wanting to pursue a separation or a divorce owing to abuse or violence", Cameroon observes that its policies aim at protecting families and at avoiding the multiple dangers of divorce and its negative social consequences. Regarding section K, on violence and abuse, Cameroon affirms that special legislative measures must be taken in order to protect the rights of persons with disabilities facing sexual and other forms of violence. As to section M, on developmental and psychiatric disabilities, Cameroon recommends that States should encourage and support the creation of organizations aiming at defending the interests of persons with developmental and psychiatric disabilities. Regarding section N, on invisible disabilities, Cameroon notes that it is important to take into

consideration invisible disabilities and to take measures in order for persons with invisible disabilities to be able to participate into social life in conditions of equality.

15. China is of the view that, while the Standard Rules had played an important historical role in advocating the rights of persons with disabilities, enhancing their status and improving their livelihood, some elements of the Rules need to be supplemented in order to take advantage of recent developments so as to ensure that the rights of persons with disabilities are fully protected and exercised. It expresses its approval of the proposed supplement to the Rules in its general content. With regard to the formulation of sections, and in particular on the ones concerning adequate standard of living and poverty alleviation, housing, health and medical care and access to the social environment (paragraphs B.13, 14 and 16, C.21 and 25, D.27, 28, 33 and 34 and G.43 of the proposed supplement), China suggests that emphasis should be placed on statements of principle, stating the direction towards which countries should try to develop. It remarks that the use of terms such as "ensure" should be avoided, in order to take into account as much as possible the different levels of economic and social development of the majority of developing and less developed countries and their available resources. China also believes that the Standard Rules and the process towards a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities should be complementary and mutually reinforcing. It is of the opinion that, as the technical norm that has guided the development of countries in areas concerning persons with disabilities for many years, the Standard Rules should continue to play their role, while the Convention should serve as an international legally binding instrument that would provide the legal guarantee for achieving the goals set forth in the Rules.

16. Cyprus acknowledged receipt of the note verbale but did not present any specific views.

17. The Czech Republic welcomes the initiative of complementing the Standard Rules through the proposed supplement and expresses its commitment to elaborate it further. As a general comment to the proposed supplement, it notes that some of the provisions presented in the proposal are unrealistic in terms of implementation by developing countries, such as, for example, rule D.29: "States should ensure that all medical, paramedical and related personnel are adequately trained and equipped to give medical care to persons with disabilities ...". The Czech Republic believes that, while it would be possible to provide medical personnel with basic information on the specific needs of persons with disabilities, it is quite unrealistic to provide all medical personnel with adequate specific knowledge on disabilities. As a consequence, the Czech Republic suggests that such a provision should be rephrased so as to urge States to establish sufficient networks of specialized centres and experts with all necessary qualifications effectively to provide medical care to persons with disabilities.

18. Regarding section A of the proposed supplement, on fundamental concepts, the Czech Republic agrees with the need to use the widest and most general classification of disabilities. However, it stresses the importance of clarifying that the term prevention should not be related to the notion of aborting a foetus with established high risk of impairment. As to section B, on adequate standard of living and poverty alleviation, the Czech Republic highlights the fact that States should,

within their capacities, also pursue positive discrimination (i.e. targeted social support) of persons with disabilities in case their disabilities constitute too great a disadvantage with respect to others in relation to equal treatment. With regard to section C, on housing, including the issue of residential institutions, the Czech Republic is concerned that provision C.21 could encourage some poor families to mutilate their children in an attempt to claim provision of housing from the State. As to section D, on health and medical care, the Czech Republic stresses that States' obligations should be realistically related to their level of development. It also considers that ensuring that persons with disabilities are informed of their rights, particularly of the right to self-determination, as stated in rule D.33, is of special importance.

19. The Czech Republic regards the inclusion of the issues of access to the social environment (section F), communication (section G) and personnel training (section H) as very important. It suggests, however, that the enumeration of disabilities included in rule G.49 should be dropped, as it would always be partial, and highlights that in such a list blindness is missing. It also suggests that rule H.55 should call for access to continuing education for all persons, including persons with disabilities. As to section I, on gender, the Czech Republic is uneasy about the reference to the fact that women with disabilities are less frequently married, despite its agreeing with the seriousness of the issue, as there is little that States can do. Regarding section J, on children with disabilities and the family, the Czech Republic suggests that J.65 should be amended by adding the words "mental and developmental" after the word "severe". With regard to section L, on older persons, it welcomes the inclusion of such an issue in the proposed supplement. As to section M, on developmental and psychiatric disabilities, the Czech Republic fully agrees that the needs of persons with such disabilities are not satisfactorily dealt with in the Standard Rules.

20. The European Union highlights that the past 10 years are believed to have brought more progress in policy development and legislation on disability than earlier decades, largely owing to the role played by the Standard Rules. It is of the opinion that this is the result of the Rules being short in format, including relatively concrete recommendations and being attached to a special monitoring mechanism, in addition to the fact that they have been elaborated in close cooperation between a large number of Government delegations and representatives of international disability organizations. The European Union indicates that the Rules have been particularly successful in clearly defining the role of the State in the implementation of measures towards full participation and equal opportunities for persons with disabilities. In its opinion, the Rules have also contributed to strengthening the human rights dimension and to providing an active monitoring mechanism within the United Nations system. As a result of the very important role played by the Rules, the European Union emphasizes the importance of keeping them as the main international guidelines for further policy development in the field of disability and therefore supports the proposal of complementing the Rules with additional provisions in the form of a supplement based on the draft presented by the first Special Rapporteur.

21. As a general comment on the proposed supplement, the European Union notes that there seems to be some overlapping between the proposed supplement and the Standard Rules. As a result, it proposes to engage in further comparison between the two texts in order to avoid duplication. In addition, the European Union notes that

neither the Rules nor the proposed supplement contain a section on mobility and transport. The inclusion of an additional section on this issue is therefore suggested. It also proposes that the supplement to the Rules should include a specific reference to accessibility of the Rules in order to make them and the supplement to them fully accessible to persons with disabilities.

22. With regard to section A of the proposed supplement, on fundamental concepts, the European Union agrees with the Special Rapporteur that the best way to achieve compatibility with the original text of the Standard Rules is to keep to the same terminology in the proposed supplement so as to avoid confusion between the original text of the Rules and the supplement. As to section B, on adequate standard of living and poverty alleviation, it highlights the importance of effectively including adequate measures to meet the needs of persons with disabilities within programmes to combat poverty and improve living conditions of the population at large. In this regard, the European Union notes that reference should be made to the Millennium Development Goals included in the United Nations Millennium Declaration. It agrees with the importance of section E, on the particular vulnerability of persons with disabilities in emergency situations. Regarding section F, on access to the social environment, the European Union notes that, while this section was not explicitly part of the mandate to complement the Rules, the inclusion of a section of this nature is justified in view of the great importance of attitudinal barriers as an obstacle to full participation of persons with disabilities.

23. As to section G, on communication issues, the European Union stresses that the role of information and communication technology in the disability field is growing rapidly, which makes it necessary to update the Standard Rules in this area. It views training personnel in the disability field as being of critical importance and therefore agrees with the inclusion of section H in the proposed supplement. The European Union is of the opinion that the proposed supplement introduces important aspects of personnel training, such as awareness and knowledge of the occurrence of violence against persons with disabilities, attitudinal barriers and knowledge about the basic living conditions of persons with disabilities. With regard to section I, on gender, it points out that women and girls with disabilities are often exposed to double discrimination and that a special emphasis on gender equality is therefore particularly relevant. As to section J, on children with disabilities and the family, the European Union stresses that the knowledge about the situation of children with disabilities has increased considerably during recent years, owing to the work done in connection with the monitoring of the implementation of the Convention on the Rights of the Child. It is therefore of the opinion that a section on these issues is highly justified both as a complement to rule 9 of the Standard Rules, on family life and personal integrity, and as an incentive to develop policies and programmes to support children and youth with disabilities. The European Union stresses the importance of the suggested measures aimed at facilitating the life of children with disabilities within their families.

24. Regarding section K, on violence and abuse, the European Union notes with appreciation the initiative to focus on these issues in a separate section and stresses the importance of both continuing research in this area and increasing awareness and knowledge of these issues among professionals. As to section L, on older persons, the European Union agrees that the supplement clarifies the need to include the specific needs of older persons with disabilities in national policies and programmes. It also states that it is important to include the situation of older

persons with disabilities in future studies and research on disability. With regard to section M, on developmental and psychiatric disabilities, the European Union notes that persons with developmental and psychiatric disabilities are among the most vulnerable in society and are often particularly exposed to prejudice and negative attitudes. It stresses that references to the needs of these two groups have been included in several sections and there therefore seems to be some overlapping between section M and several other sections. However, such overlapping could be acceptable in view of the importance of recognizing the needs of these groups. The European Union is of the opinion that the provisions introduced by the supplement on the situation of these groups represent the most important contributions of the supplement itself. Regarding section N, on invisible disabilities, it notes that this topic is not explicitly included in the mandate of the Special Rapporteur to complement the Standard Rules. However, the European Union expresses its support to the inclusion of this topic, as it puts the focus on an important phenomenon that often has a negative impact on the inclusion of persons with disabilities in society. As to section O, on suggested further initiatives in national policy and legislation, the European Union notes with appreciation the valuable recommendations presented by the first Special Rapporteur, on the basis of the experience gained during the monitoring of the Rules. It is also of the view that non-governmental organizations should be more closely involved in the process of further integration of persons with disabilities at the national level.

25. Honduras underlines the importance of the process of elaboration of a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, notably with reference to the need of ensuring the protection of the rights of persons with disabilities, for their benefit and with their participation. Honduras also agrees that the Standard Rules are the guiding instrument to end exclusion and discrimination of persons with disabilities and expresses its approval for the inclusion of the proposed supplement to the Rules.

26. Luxembourg expresses its general support to the proposed supplement to the Standard Rules and stresses the importance of consulting organizations of persons with disabilities at all stages of development and implementation of programmes aimed at persons with disabilities. Regarding section C of the proposed supplement, on housing, including the issue of residential institutions, Luxembourg states its support to the de-institutionalization of persons with disabilities. As to section D, on health and medical care, and in particular on D.33, it highlights the fact that the right of persons with disabilities to "refuse treatment and the right not to comply with forced admission to institutional facilities" should not affect the right of authorities to institutionalize persons with disabilities in case their conditions make them dangerous for themselves and for others.

27. Madagascar notes with appreciation the content of the proposed supplement and expresses its agreement on the proposals it contains.

28. Malta expresses its full support to the recommendations presented by the first Special Rapporteur in his report.

29. With regard to section A of the proposed supplement, on fundamental concepts, Oman suggests that the second edition of the International Classification of Impairment, Disabilities and Handicaps — the International Classification of Functioning, Disability and Health — be published and circulated among Member

States.[3] With reference to section B, on adequate standard of living and poverty alleviation, it notes that prevention must be viewed as general prevention through environmental health and education. In order to ensure that persons with disabilities have access to equal opportunities in education, health, employment and social services, States should elaborate specific laws on services for persons with disabilities. Training programmes should be developed and applied at the community level so as to ensure the provision of specific services. As to section D, on health and medical care, Oman notes that the need for medical personnel to give full and balanced information concerning diagnosis and treatment to persons with disabilities raises a matter of importance for them, their family and for society in general. It suggests that regular television and radio programmes should be prepared in order to maximize the dissemination of information related to disabilities. With regard to section E, on emergency situations, Oman states that emergency services should take into consideration the specific needs of persons with disabilities. Regarding section H, on personnel training, it suggests that in order to set up and support the required services for persons with disabilities and make all persons in the community aware of them, adequate training should be provided to personnel working in the private and public sectors and the training should include an understanding of the substance of the United Nations Standard Rules relating to human rights and persons with disabilities.

30. The Philippines agrees that despite the indisputable value of the Standard Rules as guidelines in developing and establishing disability policies and legislation, many inadequacies have emerged in the areas addressed in the proposed supplement, such as fundamental concepts as well as children and women with disabilities, persons with mental and developmental disabilities and communication, particularly information and communication technology. The Philippines suggests that the monitoring mechanisms for both the Rules and the World Programme of Action concerning Disabled Persons[4] should be synchronized and implemented as one activity, in consideration of the need to save time, money and effort, while at the same time improving the United Nations monitoring system in general.

31. The Russian Federation notes that the drafting and entry into force of a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities may take a long time. Therefore, it believes that prior to the completion of the Convention, the Standard Rules would remain the basic reference in the elaboration of national policies on persons with disabilities. The Russian Federation supports the initiative aimed at updating the recommendations contained in the Rules and notes that the adoption of the proposed supplement to the Rules would facilitate the progressive development of national policies and the enhancement of legislation on persons with disabilities.

32. Serbia and Montenegro is of the opinion that the report presented by the first Special Rapporteur deals with social and economic rights of persons with disabilities in a comprehensive and appropriate manner. However, it believes that more practical guidelines based on a realistic assessment of countries' needs, development level, cultural heritage, climatic conditions and environment should be developed and suggests that the Commission for Social Development prepare such guidelines.

33. Trinidad and Tobago suggests that the following areas should also be included in the supplement to the Standard Rules: accessible transportation, inclusion of

persons with disabilities in political processes, access to information and access to the legal system. It particularly welcomes the inclusion of the issues of gender violence and older persons in the proposed supplement, as they represent areas of emerging interest in the country.

IV. Summary and proposals

34. Taking into account the views of Member States, the Secretariat puts forward the following elements and proposals for the consideration of the General Assembly.

35. The majority of Member States agreed on the very important role that the Standard Rules have played during the past decade in informing the elaboration of national policies and legislation in the disability field. Member States also agreed on the fact that the extensive application of the Rules had led to experiencing shortcomings and areas in need of further elaboration. In general terms, the majority of Member States is favourable to the adoption of the proposed supplement to the Rules.

36. All Member States but one that expressed their views on the proposed supplement were of the opinion that the Standard Rules and the international convention process were not competitive but rather complementary and mutually reinforcing instruments. They therefore stressed that the Rules must continue to play their role as an action-oriented set of guidelines while progress was made towards an international convention on the rights of persons with disabilities.

37. Member States presented both general and specific comments on the proposed supplement as well as proposals for further amendments. Some Member States also presented suggestions on additional actions within the framework of the Standard Rules and on areas to be further included in the proposed supplement. The main suggestions put forward by Member States are as follows:

(a) Some Member States noted that, in order to take into account the levels of development and of available resources of different countries, emphasis should be placed on statements of principles as opposed to specific provisions;

(b) Several Member States noted that the mobilization of large financial, human and material resources was needed to ensure the efficient implementation of the Standard Rules;

(c) The mobilization of additional resources aimed at supporting national capacities on equalization of opportunities for persons with disabilities, including through the United Nations Voluntary Fund on Disability, was also considered necessary;

(d) Suggested additional areas included mobility and transport, the inclusion of persons with disabilities in political processes and access to information and the legal system;

(e) The importance of the accessibility of the Standard Rules and their supplement to persons with disabilities was pointed out;

(f) It was suggested that a further analysis of the proposed supplement and the Standard Rules should be undertaken in order to eliminate overlapping and duplication of provisions;

(g) It was proposed that the monitoring framework for the Standard Rules and that for the World Plan of Action concerning Disabled Persons should be synchronized and implemented as one activity and that cooperation between the Special Rapporteur on Disability and the various United Nations bodies and organizations involved should be strengthened and improved.

Notes

[1] The full text of the proposed supplement is contained in the annex to the present report.

[2] It should be noted that Cyprus, Luxembourg and the Czech Republic, while aligning themselves with the view expressed by the European Union also presented a contribution of their own.

[3] See World Health Assembly resolution 54.21.

[4] A/37/351/Add.1 and Add.1/Corr.1, annex, sect. VIII.

Annex

Reaching the most vulnerable: proposed supplement to the Standard Rules on the Equalization of Opportunities for Persons with Disabilities

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I. Introduction

1. The 1990s brought more progress in disability policy and legislation than earlier decades. This development was initiated through the activities in connection with the observance of the International Year of Disabled Persons (1981), the adoption of the World Programme of Action concerning Disabled Persons (A/37/351/Add.1 and Add.1/Corr.1, annex, sect. VIII) and the activities during the International Decade of Disabled Persons (1983-1992).

2. Since the adoption of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities by the General Assembly in its resolution 48/96 (annex) of 20 December 1993, and the establishment of its monitoring mechanism in 1994, the Rules have played a significant role worldwide in the elaboration of national policies and legislation in the disability field. This active and practical application of the Rules has provided new and valuable experience on how to use the Rules in the future. At the same time, it has revealed certain weaknesses and omissions in the present text.

3. Throughout the entire Standard Rules text, the term "persons with disabilities" is used to refer to persons of all ages with disabilities. In the text of the proposed supplement the term should always be understood as meaning "girls, boys, women and men with disabilities" when no other qualifying term is indicated.

4. The purpose of preparing the proposed supplement to the United Nations Standard Rules is to complement and develop the text in certain areas. The work is based on the analysis of gaps and shortcomings presented by the Special Rapporteur on Disability in his report to the thirty-sixth session of the Commission for Social Development (E/CN.5/2000/3, annex). In that analysis the following were pointed out: gender concerns; housing and communication issues; the needs of children and older persons; the needs of persons with developmental and psychiatric disabilities; and the needs of persons with disabilities in poverty situations.

5. In the process of elaborating this supplement, several international organizations and individual experts have contributed, particularly those representing the interests of persons with developmental and psychiatric disabilities and children. The panel of experts, attached to the Standard Rules monitoring mechanism, has worked with the text and made many valuable suggestions. Finally, the outcome of the global Conference on Rethinking Care (Oslo, 22-25 April 2001), organized by the World Health Organization in cooperation with the Government of Norway, has been taken into account.

6. The text of this supplement does not follow the structure of the Standard Rules. The order of sections has been chosen to avoid unnecessary repetition. The mode of presentation combines a commentary and explanation of the text with a set of recommendations, presented in the same way as in the Rules.

7. The most obvious common feature of the comments and recommendations in this supplement is that they bring into focus the needs of the most vulnerable among children and adults with disabilities.

II. Proposed supplement to the Standard Rules

A. Fundamental concepts

8. The Standard Rules include a presentation of the International Classification of Impairment, Disabilities and Handicaps, which was adopted by the World Health Assembly of the World Health Organization (WHO) in 1980. This classification has now been revised. In 2001 the World Health Assembly endorsed the International Classification of Functioning, Disability and Health, in which functioning and disability are understood to occur in a context characterized by personal and environmental factors: physical, social and attitudinal. Functioning and disability are classified at the levels of the body, the person and the society. The Classification can be used to describe an individual's capacity to execute simple and complex actions, which can be employed to determine appropriate health interventions and other changes to the person. In addition, the Classification can be used to describe actual performance in an individual's current environment. It is then possible to identify the environmental factors that facilitate or hinder that performance so as to determine appropriate environmental modifications or health-related interventions to improve it. In this supplement, however, the terminology used in the Standard Rules has been retained in order to avoid confusion.

9. It should be noted that considerable confusion has arisen concerning the use of the word "handicap". Even if the term is established in many languages, it has acquired a derogatory, negative and even insulting connotation in several languages, and should therefore be used with great care.

10. It should also be emphasized that the term "prevention", as outlined in the Standard Rules, must never be used to justify the denial of the right to life or to equal participation in society for persons who have disabilities.

B. Adequate standard of living and poverty alleviation

11. It is obvious that in developing countries, as in more developed areas, persons with disabilities and their families are more likely than the rest of the population to live in poverty. It is a two-way relationship: disability adds to the risk of poverty, and conditions of poverty increase the risk of disability. Prejudice and social stigma affect the lives of both children and adults with disabilities and lead to isolation and exclusion from the life of their communities.

12. The attainment of an adequate standard of living by persons with disabilities is implied in the principle of equal rights for all and in the process of equalization of opportunities for persons with disabilities.

13. States should ensure that persons with disabilities receive the support they need within the ordinary systems of society, such as education, health, employment and social services.

14. When taking measures to combat poverty, States should include programmes to support empowerment of persons with disabilities and promote their active participation in society.

15. As part of their development programmes, States should also ensure access to adequate and safe housing, food and nutrition, water and clothing for persons with disabilities.

16. In the framework of community-based services, States should provide education, rehabilitation, assistive devices and employment services to persons with disabilities.

17. States should encourage the collection and dissemination of information on the living conditions of persons with disabilities and promote comprehensive research on all conditions affecting the lives of persons with disabilities.

18. In cooperation with local and regional authorities, the Office of the United Nations High Commissioner for Refugees (UNHCR) and other actors, States should provide the necessary assistance to homeless persons, displaced persons and refugees with disabilities, enabling them to attain self-sufficiency and promoting sustainable solutions to their problems.

19. Organizations of persons with disabilities should be consulted at all levels in programmes affecting the standard of living of persons with disabilities.

C. Housing, including the issue of residential institutions

20. A prerequisite for full participation and equality is that persons with disabilities can grow up, live and develop their potential in the community they belong to. In this context the provision of suitable housing is crucial.

21. States should ensure safe, habitable, accessible, affordable housing and shelter for all persons with disabilities, adequate for their health and well-being. Such housing conditions, including the social and physical infrastructure, should enable children with disabilities to grow up with their parents and should enable adults with disabilities to be part of the community.

22. Measures should also include awareness-raising campaigns to combat negative attitudes among neighbours as well as the local population.

23. In countries where the policy has been to house many groups of persons with disabilities in separate and large institutions States should reorient their policies towards community-based services and family support. In this way it should be possible to initiate programmes to stop admissions to such facilities as well as plan for their ultimate closure.

24. For orphans with disabilities and for other groups of disabled children without family or other personal support, substitute families should be found. For adults in the same situation, small family-like facilities (group homes), situated in the community, should replace large institutions.

25. States should ensure that appropriate support is provided for residents with disabilities when they leave their residential institutions to rejoin the community, and that the support services continue for as long as required.

26. With regard to persons still living in institutions, States must ensure that their basic needs are met, and ensure respect for their right to a private space where they may receive visitors as well as keep their files, correspondence and other personal belongings. The treatment of every person should be directed to preserving and

enhancing personal autonomy. States must also ensure that opportunities for meaningful participation and involvement in community life occur.

D. Health and medical care

27. Recognizing that health is a human right, States must ensure access to high quality and safe medical services and facilities for all people, regardless of the nature and/or severity of impairment, age, gender, race, ethnicity and sexual orientation. States should recognize that persons with disabilities have the same right to self-determination as other citizens, including the right to accept or refuse treatment. States must ensure that the right to life is paramount in the delivery of medical and health services.

28. States should ensure that persons with disabilities get the same level of medical care within the same system as other members of society, and do not face discrimination on the grounds of presumptions of their quality of life and potential.

29. States should ensure that all medical, paramedical and related personnel are adequately trained and equipped to give medical care to persons with disabilities and that they have access to relevant treatment methods and technology. To understand fully what it means to live with a disability, future professionals should meet and learn from persons with disabilities.

30. Medical and paramedical personnel should give full and balanced information and advice concerning diagnosis and treatment to persons with disabilities. This is particularly important in the situation of prenatal diagnosis. In the case of children, information should be given to parents and, when appropriate, to other family members.

31. States should design and implement programmes with the full involvement of women and men with disabilities to give them appropriate and fully accessible education, information and services to address their reproductive and sexual health needs.

32. States should raise awareness of, prevent and treat sexually transmitted infections, including HIV/AIDS.

33. States should ensure that medical facilities and personnel inform people with disabilities of their right to self-determination, including the requirement of informed consent, the right to refuse treatment and the right not to comply with forced admission to institutional facilities. States should also prevent unwanted medical and related interventions and/or corrective surgeries from being imposed on persons with disabilities.

34. States should develop national rehabilitation programmes for all groups of persons with disabilities. Such programmes should be based on the actual individual needs of persons with disabilities. The training should be based on the principles of full participation and equality, and aim at the removal of barriers for their participation in the mainstream of community life.

E. Emergency situations

35. It has often been recognized that the needs of persons with disabilities are forgotten or neglected in general relief programmes.

36. In cooperation with concerned United Nations agencies such as UNHCR and the United Nations Development Programme (UNDP), States should develop policies and guidelines for the inclusion of support measures with regard to persons with disabilities in emergency situations. Their emergency services should be adequately equipped and prepared to provide medical treatment and support to persons with disabilities and their families.

37. Special attention should be paid to the fact that persons with disabilities are particularly vulnerable to abuse in emergency situations.

F. Access to the social environment

38. Two dimensions of accessibility are pointed out in Rule 5 of the Standard Rules: access to the physical environment and access to information and communication. Experience has shown that it is necessary to include a third dimension — access to the social environment — in national disability programmes.

39. States should encourage measures to remove all obstacles resulting from ignorance and negative attitudes towards persons with disabilities.

40. Measures to combat prejudice should be taken through public education and information campaigns, awareness-raising and encouragement of a positive portrayal of persons with disabilities in the media. Particular emphasis should be given to the gender dimension, to persons with developmental and psychiatric disabilities, to children with disabilities and to persons with multiple or invisible disabilities.

41. When planning measures to combat social prejudice, it is of particular importance for States to ensure the involvement of organizations of persons with disabilities.

G. Communication issues

1. Information and communication technology

42. Information and communication technologies and infrastructures are rapidly growing in importance in the provision of information and services to the population. These technologies must therefore be made accessible and their great potential to assist and support persons with disabilities must be utilized.

43. States should ensure that information and communication technologies and service systems offered to the general public are either made initially accessible or adapted to be made accessible to persons with disabilities. It is also important to create opportunities for special training courses as well as access to affordable equipment and software and to distance learning through these technologies for persons with disabilities.

44. States should consider presenting accessibility and usability standards and guidelines as a precondition for public funding and recognize public procurement as a tool to achieve accessibility.

45. States should initiate the development and use of special technical and legal arrangements to make information and communication technologies accessible to persons with disabilities.

2. Sign language

46. During the 1990s an increasing number of States recognized sign language as the main means of communication for deaf people. In view of the decisive importance of sign language in the personal development of deaf people, such recognition must be encouraged worldwide.

47. States should recognize sign language as a natural language and as the medium of communication among deaf people. It should be used in the education of deaf children, in their families and in the communities.

48. Sign language interpretation services should be provided to facilitate communication between deaf persons and others.

3. Other communication needs

49. Consideration should be given to the needs of people with other communication disabilities, such as the speech-impaired, the hard-of-hearing, the deaf-blind and persons with developmental and psychiatric disabilities, who require specific forms of assistance.

50. In addition to information and communication technologies, special assistive devices and interpreter services may be needed.

H. Personnel training

51. A key element in all programmes and services for persons with disabilities is to have well-trained and informed personnel. Furthermore, information on disability and the living conditions of persons with disabilities should be provided to professional groups serving the general population, such as medical doctors, teachers and social workers as part of their basic training. In addition to technical information, professionals should have knowledge of the prevailing attitudes towards persons with disabilities.

52. States should ensure that all authorities providing services in the disability field give adequate training to their personnel and that an understanding of the substance of the United Nations Standard Rules is an outcome of such training.

53. States should ensure that personnel are educated to recognize acts of discrimination based on gender, ethnicity, race, age and/or sexual orientation against children and adults with disabilities.

54. States should facilitate training for persons with various types of disabilities so they may work as professionals in the disability field and serve as role models.

55. Access to continuing education on a regular basis should be available and encouraged for all persons, groups and institutions concerned with disabilities.

I. Gender

56. Women with disabilities are often exposed to double, or even triple, discrimination. They suffer discrimination as women, as disabled persons and on the grounds of their economic status.

57. In many cultures, the status of women with disabilities is negatively affected by the fact that they less frequently get married and have children. They are often exposed to discrimination in medical care and rehabilitation, education, vocational rehabilitation and employment.

58. The initial sentence of every Rule in the Standard Rules document contains the term "persons with disabilities". This should always be understood as referring to "girls, boys, women and men with disabilities". It is important to emphasize both gender equality and the inclusion of children and youth, wherever appropriate.

59. In gender-sensitive development programmes, women and girls with disabilities should be identified as target beneficiaries.

60. Organizations of persons with disabilities should take action to get the concerns of women and girls with disabilities onto their agenda, and onto the agendas of women's organizations and organizations representing children.

J. Children with disabilities and the family

61. In some cultures, a disability is often seen as a punishment and is connected with feelings of fear and shame. Owing to this, children with disabilities may be hidden away or neglected by the rest of the community. As a consequence it is not possible for them to live a decent life, and they are sometimes even denied the right to survival.

62. Children with disabilities are often neglected by the school system. Obstacles in the physical environment prevent the children from moving around freely, from playing and from sharing the company of other children.

63. States should initiate programmes for early detection and intervention and ensure that children with disabilities, including children with severe and/or multiple disabilities, have access to medical care and rehabilitation services. These services should be provided without any bias based on gender, age or other status.

64. Training and rehabilitation programmes should not disrupt the disabled child's right to family life and social interaction with their non-disabled peers.

65. All children with disabilities, including those with severe disabilities, should have access to education. Special attention should be given to very young children, girls and young women with disabilities.

66. States should encourage measures that enable children with disabilities to play and to be together with other children in the community.

67. States should ensure that children, adolescents and youth with disabilities are entitled freely to express their views on matters of concern to them and to have their views taken seriously in accordance with their age and maturity.

68. States should develop adequate support to families who have children with disabilities, including disability-specific assistance and information, access to mainstream parent support and possibilities for parent-to-parent exchanges.

69. States should encourage employers to make reasonable adjustments to accommodate family members responsible for the care of children and adults with disabilities.

70. States should support women and men with disabilities wanting to pursue a separation or a divorce owing to abuse or violence.

K. Violence and abuse

71. Studies during recent years have shown that experience of sexual abuse and of other forms of violence and abuse are frequent among persons with disabilities. Owing to the special circumstances, such problems are often difficult to discover, as they may occur in closed environments and are sometimes committed against children and adults who have difficulty explaining what has happened.

72. States should develop programmes to recognize and eradicate abuse and violations of girls, boys, women and men with disabilities. It may occur in the family, in the community, in institutions and/or in emergency situations.

73. Persons with disabilities need to be educated about how to avoid the occurrence of abuse, how to recognize when abuse has occurred and how to report it.

74. States should provide information to persons with disabilities and their families about ways to take precautions against sexual and other forms of abuse.

75. Professionals should be trained how to identify conditions leading to possible victimization, how to avoid such situations, how to recognize when abuse has occurred, how to support a victim with a disability and how to report on such acts.

76. Police and judicial authorities should be trained to work with persons with disabilities so that they can receive testimonies from such persons and treat instances of abuse seriously. Perpetrators of abuse should be identified and brought to justice.

77. Special legislative measures may be needed to protect the right to personal integrity and privacy for children and adults with disabilities, in order to avoid their exploitation and abuse.

L. Older persons

78. There are two main categories of older persons with disabilities. For those who experienced their disabilities earlier in life, the needs may change with advancing age. The other group consists of people who lose physical, sensory or mental functions due to ageing. With the increase in life expectancy, owing to the general improvement in the standard of living, this group is growing in number.

79. The Standard Rules do not make any age distinctions. The term "persons with disabilities" refers to persons of all ages. However, experience has shown that the

needs of older persons with disabilities are often not included in national disability policies and programmes, and therefore some clarification may be appropriate.

80. States should ensure that the needs of older persons with disabilities are included in the policies, programmes and services designed to meet the needs of persons with disabilities.

81. Special attention should be paid to the needs of older persons with disabilities in the provision of health and medical care services, rehabilitation, assistive devices and other forms of support services.

82. The situation of older persons with disabilities should be included in research, in the collection of statistics and in the general monitoring of the living conditions of persons with disabilities.

83. Public information and awareness-raising campaigns should pay attention to the situation of older persons with disabilities.

M. Developmental and psychiatric disabilities

84. The two groups of persons, those with developmental and those with psychiatric disabilities, are different in regard to both the origin and the character of their problems. However, both groups belong to the most vulnerable among citizens of society. Their disabilities are surrounded with more negative attitudes and prejudice than most other groups of persons with disabilities. Particularly in developing regions and in countries with economies in transition, the voice of persons with developmental and psychiatric disabilities is seldom heard. Consequently, their needs are often forgotten or neglected when plans are made to improve the living conditions of persons with disabilities.

85. One of the more serious weaknesses of the Standard Rules is that the needs of persons with developmental and psychiatric disabilities are not dealt with in a satisfactory way. Areas such as health and medical care, rehabilitation, support services, housing conditions, family life and personal integrity are of vital importance for both these groups. Their needs constituted an important perspective when these policy areas were elaborated for this supplement.

86. States should ensure that the special needs of persons with developmental and psychiatric disabilities are respected in health and medical care, and in rehabilitation and support services. Particular emphasis should be given to issues of self-determination.

87. States should develop forms of support for families who have children or adult family members with developmental or psychiatric disabilities. Such support may be necessary to make it possible for the disabled person to live with the family.

88. Many adults with developmental or psychiatric disabilities need special housing arrangements to be able to cope with their situation. Small family-like facilities (group homes) with sufficient support services, sometimes provided within the framework of independent living schemes, may be useful alternatives.

89. States should ensure that the situation of persons with developmental and psychiatric disabilities is included in research, data collection and general monitoring of the disability field.

90. States should encourage and support the development of organizations representing the interests of persons with developmental and psychiatric disabilities, including self-advocacy groups and parent action groups.

N. Invisible disabilities

91. An important group of persons with disabilities are those who have disabilities that are not easily discovered by others. This often leads to misunderstandings and wrong conclusions. Among such groups with invisible disabilities, the following may be mentioned: persons with psychiatric or developmental disabilities; those with disabilities from chronic diseases; and those who are hard of hearing or deaf.

92. In public awareness programmes, it is important to include information about persons with invisible disabilities and the special problems they may experience.

93. It is also important to include the unique characteristics of invisible disabilities when taking measures towards full participation and equal opportunities for persons with disabilities.

O. Suggested further initiatives in national policy and legislation

94. As a result of the experience gained in the use of the Standard Rules for a number of years and as a consequence of the development in the human rights area, the following general recommendations concerning governmental policy can be made:

(a) States should introduce comprehensive mandatory anti-discrimination laws to secure the removal of obstacles to equal participation in mainstream community life by persons with disabilities. They should ensure the inclusion of persons with disabilities among indigenous peoples and other minorities in this process;

(b) States should consider the introduction of mandatory legislation to ensure the provision of assistive technologies, personal assistance and interpreter services, according to the needs of persons with disabilities, and those of their family caregivers, as important measures to achieve equal opportunities;

(c) States should consider the use of public procurement as a tool to obtain accessibility. Accessibility requirements should be included in the design and construction of the physical environment from the beginning of the designing process;

(d) Legislative measures should also be considered to encourage and support the development of accessibility in transportation systems, housing, and information and communication services;

(e) States should support and promote the international exchange of research findings and experiences and the dissemination of best practices in all sectors of society;

(f) States should take action to include reporting on the situation regarding persons with disabilities in their periodic reports to the committees of the various human rights conventions to which they are parties. Information should be gathered

and submitted whether or not articles in each convention refer specifically to persons with disabilities. States should support the participation of organizations of persons with disabilities and encourage them to express their views during the review process;

(g) Before making decisions on policies, programmes and legislation that affect the lives of the population generally, consequence analyses concerning the effects on persons with disabilities should be made.